

A CAREGIVER'S PERSPECTIVE

By
Katryna Gould

Good morning. I am grateful for the opportunity to speak to you today as a caregiver, a job I began in 1990. I hope that the various messages you hear this morning will be helpful to you as you continue your work that has an enormous impact on the lives of aged Americans and those of us who care for them.

I have cared for my husband's mother and both my parents. My experiences with each of them have been very different as you'll see as I introduce you to our family. As is the case with many of us, I began my time as a caregiver without professional training or portfolio. After my husband and I were married, his mother, Katherine, came to live with us. At 84 she gamely explored her new neighborhood in the nation's capital and found a volunteer job in the Children's Room of the local library. My husband and I continued our careers, still meeting most days for lunch but occasionally using that time for Katherine's doctor or dentist visits. In addition, each day now included a call or two to her to say hi and see how she was progressing with her latest project -- figuring out how to meet a particularly confusing requirement on her tax return or working tirelessly to recall the Latin word-teaser poem she learned as a young girl.

We welcomed a third generation into our home the following year when our son was born. At the end of my maternity leave, I left my job as project manager for our local electric utility company and became resident manager of our multi-generational living facility. As our son grew older and more independent, we watched his grandmother grow younger, and the balance of care we were providing shifted. I found that my own days were become more and more structured to meet Katherine's needs.

Fortunately, our family physician thoughtfully considers the impact of the personal, living and social circumstances of his elderly patients. He spoke to Katherine and to us of the need for her to maintain social contacts as the boundaries of her own world grew smaller with the end of her days of unescorted walks in the neighborhood. He also spoke of the need for more structure in her routines than her once a week job in the library offered. And he introduced us to the special world of adult day services.

This marked a new stage of caregiving for me. Katherine began attending the IONA Adult Day Health Center not far from our home. I was now sharing Katherine, who had become my constant companion, with professionals experienced not only in working with aged and disabled adults in need of care, but also with those of us who cared for them. Most importantly, for me, the watchfulness of the day center's staff extended to me as Katherine's caregiver. They answered all my questions (many before I asked them), addressed all my comments, and offered all manner of resources from social workers and nurses to books to read. They also invited me to participate in their first caregivers' support group – an invitation I gladly accepted.

We were quite a group -- several were women caring for a frail, elderly husband; one a woman caring for her elderly mother in the early stages of dementia; an elderly woman caring for her daughter who had suffered a stroke before the age of fifty; a middle-aged woman caring for her diseased and disabled middle-aged husband; a woman caring for her aged parents who lived 200 miles away; and me, the mother of a pre-schooler, caring for my mother-in-law. For an hour a week we came together in need and talked – sometimes tearfully, sometimes angrily, sometimes overcome with laughter, the only response in our frequently absurd world. We spoke of our fears, our frustrations, our questions, and our accomplishments...and of our loneliness and isolation in the midst of a life that rarely offered a moment alone. Most of all, it was our time, spent in mutual understanding and support, with no interruptions.

The offer to meet with a social worker was another matter. As resident manager, wife, mother, and daughter-in-law, I gave our home facility and all it offered high marks, and politely declined. Over time, however, I began looking at our home with a critical eye, mentally calculating the skid potential of our rugs, trying to visualize what grab-bars would do to our décor! I decided that the bars were necessary only in the shower but I found no relief from the fear that Katherine would fall and injure herself. I went to the local home improvement center and was delighted to find a whole section devoted to elder safety – the equipment and aides covered every contingency but there was no one to advise me on their proper placement and use for a five-foot tall woman who weighed under 100 pounds. It was time to call for the social worker. She began with an interview designed to elicit information about our family and our home life. As soon

as she was finished, I launched into all the questions and matters on my mind, particularly how best to deal with that pesky rug skid potential. She stopped me short and pointed out that just because I was a well-educated, caring, career woman, it didn't mean that I could or should try to be working at the level of detail I was drawn to – nor should I be trying to both ask and answer the questions. Be the caregiver, she said, ask the questions and let us respond to you. You wouldn't have tried to be your own resource for a technical area at work you didn't know, she admonished me, why on earth try it now. It was then and remains now among the best pieces of advice I have ever been given.

Katherine's days at IONA meant time for me to be mother, homemaker and wife with an ease that would otherwise not have been possible. When her nights also required our full-time attention, we knew we could not carry on alone. We located overnight carers and began another new routine for our family. Katherine's last months were spent surrounded by family, friends, and caregivers. She died at home at age 92, with dignity and love.

Caring for my parents has been very different. While Katherine's last years of life were marked by mostly gentle declines, both my parents were stricken with debilitating illnesses. In my father's case, his last illness was preceeded by a fall that resulted in two months of hospitalization and rehabilitation. I found myself managing our home as well as my parents' while my mother sat with my father and encouraged him and we all celebrated his return home for Thanksgiving of 2002. Exhausted, they both settled in to a new life, each needing to take most of the day to accomplish the simplest of routines. I too was exhausted, but found that I needed most was the care support that I had found at IONA. I was surrounded by friends who were thoughtful, caring, and willing to help but I was too worn down to organized them to support me. Two months later, just as we all were finding our way more easily, my father was diagnosed with terminal pancreatic cancer. Thirteen days later, he died peacefully at home – constant care and companionship provided by my mother, my husband, my son, me, and Doris, who had been constantly by Katherine's side at the end of her life.

As we struggled to cope with the swift loss of my father, we realized that my mother, thought to be forgetful and confused due to the stresses of caring for my father, in fact was herself slowing down significantly. Before another six months passed, she became ill and moved in with us. This time, our care was not enough, and following a brief hospital stay, my mother moved to an

assisted living facility where she could have physical therapy to strengthen her weakened body, and a structure within which she could begin to reestablish her daily routines. As her body and mind struggled against the onslaught of side-effects of medication needed to preserve her eyesight, her spirit was diminished but never broken. In time, as her illness receded, her zeal to maintain as much self-determination as possible returned.

I, too, found self-determination to once again be part of my life as I was freed of the urgencies of being a full-time caregiver. With delight, I turned to the joys of being a wife, mother, homemaker, volunteer at church and school, friend, walker and gardener, with new-found flexibility. When I broke my foot in two places because I'd not been a long-distance walker for a while and my body couldn't keep up with my enthusiasm, the consequences weren't overwhelming. I turned to gentler activities and carried on. But just for a while.

I'm sure I don't need to tell those of you assembled here that as caregivers, we aren't typically given two weeks notice that our services will be needed. As I write this, my mother is in her hospital bed just a few miles away recovering from emergency surgery at midnight last Sunday. Her new-found security and re-claimed independence are suspended and her world seems shattered. Another chapter has begun. I am a caregiver, there is no outline for what will be written.

Thank you.

Washington, D.C.
December 15, 2003